

# GENE NEWS

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INSIDE THIS  
ISSUE

Pg 2. National  
DNA Day

Pg 3. Genetics  
Nurses

Pg 3. Coordinator's  
Corner

Pg 4. Resources  
for Providers



## *Caring for Our Neighbor Island 'Ohana...*

Since November 2005, the Hawai'i Genetics Program and Hawai'i Community Genetics have been piloting a Practice Model for the provision of pediatric and adult genetic services. The purpose of this Practice Model is to bring clinical genetic services to families living far from urban medical centers. Because all clinical geneticists and genetic counselors are located in Honolulu, neighbor island families who need a genetics consultation must fly from their home island to O'ahu. This can be very expensive and time consuming, and can be especially difficult for families caring for children with special needs and other family members.

To make genetic services more accessible to our neighbor island families, a geneticist and genetic counselor visit a neighbor island site monthly to hold one-day clinics. Kaua'i, Maui, Hilo and Kona are regularly scheduled, and Waimea and Moloka'i were recently added as sites. Feedback from all of the clinics has been very positive!



“Having the doctor come to Kona has made it very convenient for us. We did not have to pay for plane fare and we did not have to take a day off from work. We feel very fortunate and grateful that Dr. Seaver was able to see us here in Kona. Because our resources are so limited on the outer islands, it was great to have the doctor come to us. I know many families might not be able to have a genetics appointment unless Dr. Seaver comes to Kona.”

“[Telemedicine made it easier because] I was able to ask questions and speak to the specialist one-to-one without having to fly up and finding accommodations. This has been very helpful and, without it, it would have been difficult for us to be seen.”



Besides the neighbor island outreach clinics, the Practice Model also includes a half day telemedicine clinic each month. Using videoconferencing equipment, a geneticist and genetic counselor in Honolulu can “see” a family in Kaua'i, Maui, Hilo, Moloka'i or Kona in real-time, without the travel expenses.

Information from the families, primary care providers and the genetic specialists is being collected and evaluated as an integral part of the Practice Model. The data will be used to help determine the best service delivery model for O'ahu and the neighbor islands so that comprehensive genetic services can be provided to all families in Hawai'i.

As part of the same federally funded project, we are planning to expand our Practice Model activities to Guam later this year. A geneticist and genetic counselor will conduct a week-long Guam genetics clinic and will initiate telemedicine with patients there.

We are all very excited about the Practice Model activities. Similar activities are being conducted in other states, including Oregon, Washington, Alaska, and Idaho. We hope that our efforts will ensure that any family who would like to receive clinical genetics services will be able to do so, no matter where they live!

Linda Lingle,  
Governor of Hawai'i

Chiyoeme Leinaala Fukino, M.D.  
Director of Health



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## Webcasts

The NHGRI has produced webcasts to help students and teachers better understand genetics, genomics and the impact of the Human Genome Project. Some webcasts include:

### 1. **Genomics: Towards a Healthier You:**

NHGRI Researcher Barbara Biesecker talks about genomics and your health

### 2. **The Genome Era: That it Means to You:**

NHGRI Director Francis Collins talks about genetics and interesting aspects of the field.

### 3. **The Power of Comparison: Unleashing the Dog Genome:**

NHGRI researcher Dr. Elaine A. Ostrander talks about comparative genomics.

### 4. **Life in the Lab:**

Learn what it is like to choose a scientific career from three young and very different individuals who decide to invest their lives in research.

### 5. **DNA - The Next Generation:**

Nobel laureate James Watson and NHGRI Director Francis Collins discuss the history and future of human genetics.

## National DNA Day: April 25<sup>th</sup>, 2007

National DNA Day is a day when students, teachers and the public can learn more about genetics and genomics! National DNA Day celebrates the completion of the Human Genome Project in April 2003, and the discovery of DNA's double helix. National DNA Day is sponsored by the National Human Genome Research Institute (NHGRI), in cooperation with the American Society of Human Genetics [ashg.org], the Genetic Alliance [geneticalliance.org] and the National Society of Genetic Counselors [nsgc.org].

To access these great resources, please visit the National DNA Day website at:

**www** .genednet.org/pages/k12\_dnadayabout.shtml

The NHGRI has produced webcasts to help students and teachers better understand genetics, genomics and the impact of the Human Genome Project. The webcasts are listed to the left.

Local scientists and genetics experts are willing to give presentations. You can browse through the online ASHG Mentor Network. Presenters from Hawai'i are available to visit your classrooms!

On April 25, 2007, you can join NHGRI researchers in a live, online chatroom. Some of the world's leading genetics researchers will be available to answer questions.

National DNA Day "Teaching Tools" are also available on the website, including slide presentations, instructions for the 2007 DNA Day Essay Contest, online multimedia education tools that explore the Human Genome Project, genetics education modules for teachers, information about mentorship programs, and curriculum supplements.

**For questions about DNA Day or the DNA Day resources, please send an e-mail to** DNAday@mail.nih.gov. For questions about local experts and presentations, please contact Kirsty McWalter: kirsty@hawaiiigenetics.org. Enjoy DNA Day!



Check out these DNA Day webcasts at  
[http://www.genednet.org/pages/  
k12\\_dnadayabout.shtml](http://www.genednet.org/pages/k12_dnadayabout.shtml)





## Genetics Nurses – Specialized Care

*This is the fourth installment of a continuing series of articles describing the various roles of genetics professionals. We hope the information will be useful for healthcare providers referring for genetic services, families who are referred for genetic services, and those considering a career in genetics.*

Families affected with genetic diseases often require lifelong medical management and support from their genetics health care team. Genetics nurses usually act as the person of contact for families and create a holistic approach to supporting these families.

During diagnosis, genetics nurses may often obtain detailed family and medical histories, assess and analyze hereditary and non-hereditary risk factors and provide genetic information and psychosocial support to individuals and their families. In follow-up, genetics nurses provide ongoing nursing care and support to their families whether in the hospital or at a doctor's office, updating them about their health and ensuring all treatments and interventions are coordinated. Outside of the clinic, some genetics nurses are involved in research, teaching, consumer groups, public policy and administration.

A genetics nurse has a Master's degree in genetics and is licensed as a professional registered nurse. Some pursue additional credentials by the Genetic Nursing Credentialing Commission (GNCC), an affiliate organization of the International Society of Nurses in Genetics. With the volume of new information that is being discovered in the field of genetics and applied to medicine, nursing programs across the US have included genetics education within their curriculum and are offering post-baccalaureate certificate and graduate degrees in genetics nursing.

There is currently one licensed nurse in Hawai'i who provides genetics services with Hawai'i Community Genetics and Tripler Army Medical Center. She plays a vital role in managing newborns and children who are detected by newborn screening to have a metabolic disease.

**If you are interested in more information about this profession, please go to:**



International Society of Nurses in Genetics:  
<http://www.isong.org/resources/credentialing.cfm>

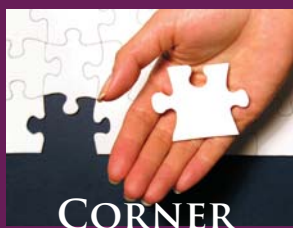
Genetic Nursing Credentialing Commission  
<http://www.geneticsnurse.org/home.html>



American Academy of Nursing  
<http://www.aannet.org/>

American Nurses Association  
<http://www.nursingworld.org/>

## COORDINATOR'S



After a busy first quarter of writing grant applications and reports, we continue to keep busy with a lot of new activities. This seems appropriate for the Spring. Our neighbor island genetics clinics and telehealth sessions are continuing to expand. The families on the neighbor islands really appreciate having accessible genetic services on-island.

We're expanding our website to make a web-based version of our Teachers' Genetics Resource Kit. This will make the kit accessible to more teachers in the state.

The Newborn Metabolic Screening Program continues to research adding Cystic Fibrosis (CF) screening to the state panel. The advisory committee has supported early detection and treatment to improve health outcomes for newborns detected with CF.

Finally, our genetics staff is available if you need a speaker for your class or group even when it's not DNA Day.



Please contact me if you have further questions or comments.  
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## Looking for Genetic Resources?

**Hawaii Genetics Program**  
[www.hawaiiigenetics.org](http://www.hawaiiigenetics.org)

- Information about genetic services in Hawai'i
- Links to the newborn metabolic screening and birth defects programs
- Descriptions of projects underway at the Department of Health
- Educational resources

*There are many websites that provide genetics information. It can be difficult to know where to start. We have listed some websites that are good sources of both patient and provider information.*

### **American Academy of Pediatrics**

<http://www.aap.org/>

- Professional education and resources
- Clinical guidelines and policies developed by the Academy

### **Genetics Home Reference**

<http://ghr.nlm.nih.gov/>

- Patient-friendly information on several genetic disorders
- Basic information about genes, chromosomes, and inheritance patterns

### **Genetic Alliance**

<http://www.geneticalliance.org/>

- Support group information for families living with genetic disorders
- Information regarding advocacy, education, and empowerment

### **Genetests**

<http://www.genetests.org>

- Information regarding genetic conditions including disease characteristics, diagnosis, management, molecular basis, genetic counseling, and testing information
- A testing and genetics laboratory directory

### **March of Dimes**

<http://www.marchofdimes.com/professionals/>

- Fact sheets for providers

### **STAR-G**

[www.newbornscreening.info](http://www.newbornscreening.info)

- Parent fact sheets for disorders detected by newborn screening
- General information about expanded Newborn Screening